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ARTIKEL

The National Prostate Cancer Register of Sweden

Basis for quality assessment, quality improvement, and research

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Abstract Cancer quality registers are attracting increasing attention as metrics for quality assurance and improvement. Comprehensive, high-quality data in nationwide population-based registers are also an ideal basis for observational studies. Here we describe the organization of the National Prostate Cancer Register (NPCR) of Sweden as well as some examples of reports and results from analyses based on NPCR and other health-care registers.

Keywords National Prostate Cancer Register (NPCR) Sweden · Prostate Cancer data Base Sweden (PCBaSe) · clinical cancer register · prostate cancer · dashboard panel · online registration

A recent surge in interest in the data available from quality registers in Sweden in many fields led to an increase in the financial support to quality registers between 2012 and 2016. Currently, more than 80 quality registers in various fields of medicine are funded by the Swedish Association of Local Authorities and Regions [1].

These quality registers can broadly be divided into two categories: registers for specific diagnoses and registers of surgical procedures. Several of these registers have had a major impact on clinical practice in Sweden. For example, the Swedish Hip Arthroplasty Register initiated in 1979, a procedure-specific register, has had a strong impact on the quality and long-term outcomes following hip implant surgery [2]. The revision rate of hip implants in Sweden, which is the lowest in the world, is attributed to the systematic feedback on the failure rate of different implants. Another example of a successful use of a quality register is the register-based randomized clinical trial, i. e., a trial in conjunction with a register in which outcome is assessed by use of data in a register. This study design has been successfully pioneered in the cardiovascular field [3]. In comparison with the procedure-specific hip register and registers of myocardial events in which the time to many crucial events is short, selecting appropriate quality indicators for prostate cancer care that can be assessed shortly after diagnosis and treatment is more challenging since disease progression and death from prostate cancer mostly occur many years after diagnosis.

Cancer quality registers, aka clinical cancer registers, have been developed in some countries. These registers collect data that are intended to be used as metrics for quality assurance and quality improvement [4]. To meet these goals, data collection needs to be complete and data must be rapidly collated and reported back to each department. Furthermore, relevant quality indicators of care must be selected, and these should then be reported in a user-friendly format. Quality indicators are ideally selected from national and international evidence-based guidelines, for which the medical profession has reached a consensus.

In addition to serving as metrics for clinical quality assurance, quality improvement and benchmarking between different health-care providers, comprehensive data on cancer characteristics and cancer treatment collected in clinical cancer registers are an ideal basis for observational studies.

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In this paper the development and organization of the National Prostate Cancer Register (NPCR) of Sweden, a clinical cancer register, are described and some examples of reports and results from analyses based on NPCR and other health-care registers are provided.

History and set-up of the NPCR of Sweden

In 1987 the first Regional Prostate Cancer Register was set up in the South-East health-care region of Sweden. Other health-care regions joined and since 1998 all six health-care regions in Sweden have been participating in the NPCR. In the NPCR, detailed data on diagnostic work-up, cancer characteristics, and primary treatment are registered for 98% of all prostate cancer cases compared with the Swedish Cancer Register, to which reporting is compulsory and mandated by law. Since 2000, tumor differentiation has been registered according to the Gleason classification, and from 2007 data on prostate volume, number of biopsies, number of biopsies positive for cancer, and total linear extent of cancer in the diagnostic biopsies are also registered. Curatively intended radiotherapy has been registered in detail in a separate form since 2007. In 2015, a separate form for radical prostatectomy (RP) was introduced, also allowing for registration of RP performed after an initial period of active surveillance. Registration in the NPCR is performed by designated staff at each department, usually secretaries or nurses, at each department. In recent assessments, data in the NPCR were found to be complete, representative, and of overall high quality [5–7]. Information on the registered variables can be found on the NPCR website (www.npcr.se) in Swedish and in English.

Organization of work in the NPCR

The work of the NPCR is led by a steering group with two representatives, one urologist and one oncologist, from each of the six health-care regions in Sweden. In addition, experts in various areas including surgery, radiotherapy, pathology, epidemiology, quality of life research, and biostatistics as well as two patient representatives are also part of the steering group. As a platform for registration, NPCR has been using the Information Network for Cancer Care (INCA), the national quality register platform for cancer quality registers since 2007. Data on more than 400,000 cancer cases are held at INCA, which is used as platform for more than 30 Swedish quality registers. Since INCA holds sensitive personal information on an individual level, access is limited to authorized staff at reporting units. Registration is made by use of four different forms online: one diagnostic form, one form for work-up and medical treatment, and separate forms for radiotherapy and radical prostatectomy. These forms have several logical controls, for example, dates for procedures are checked for chronology. As of January 2015, data are entered directly into the NPCR database at INCA as a default and uploaded and displayed within 24 h. Subsequently, data are monitored for capture and completeness by staff at each RCC. Data are requested from the urological department for men who have been diagnosed with prostate cancer based on morphological examination at a pathology department but who have not been reported to the NPCR.

The NPCR is supported by the Confederation of Regional Cancer Centres and the National Center for Prostate Cancer is at RCC Uppsala where there is a support team with a coordinating nurse and a biostatistician. From a legal point of view the responsible agent for a quality register is the authority that holds the register. For NPCR it is the county council of Uppsala. Thus, data are held at the INCA. For research it can then be exported from the INCA after approval of a Research Ethics Board. Each year, the NPCR arranges retreats for reporting staff at urology and oncology departments in Sweden with the ultimate aim of improving the quality of registration. This retreat usually starts around 6 p.m. with a keynote presentation based on the NPCR, having dinner and time to interact socially, which is extremely important for the registration staff; on the following day there is a full-day workshop on registration.

An annual report with data presented at department level is publicly available at www.npcr.se in Swedish and in an English version without comments. The report consists of comparisons between health-care providers, departments, counties, and regions and also nationwide changes over time. Three examples of the latter type of figures are demonstrated in Fig. 1. In addition to the annual report that is 100+ pages, a short newsletter that targets administrators, patients, and the general public highlights an important aspect of the annual report. In December 2016 an online report was launched and can be accessed on the NPCR website. In this interactive report, the viewer creates exactly the specific report he/she wants to see, e.g., the change in frequency of radical prostatectomy at a specific hospital for high-risk prostate cancer in men 70–80 years old from 2007 to 2015.

Patient-reported outcome and experience measures

Since 2007, PROM questionnaires have been made available for distribution to men who undergo curative treatment. Each department has to distribute baseline questionnaire to be filled in before treatment, whereas subsequent follow-up questionnaires are centrally distributed. The capture rate

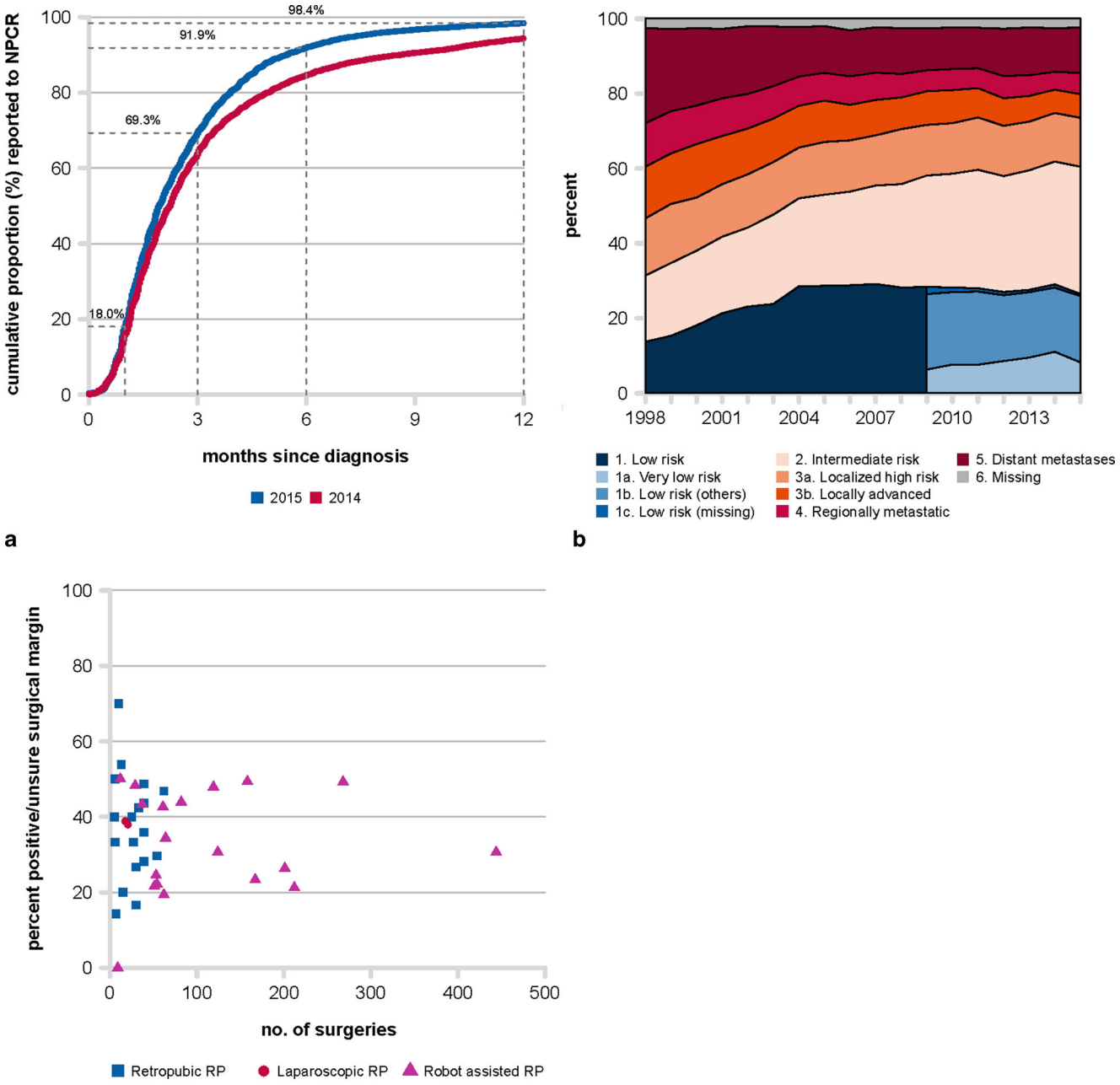

Fig. 1 **a** Time between diagnosis and registration in the NPCR for cases of prostate cancer in 2014 and 2015. **b** Proportion of cases according to prostate cancer risk categories 1998–2013. **c** Relationship between hospital surgical volume of radical prostatectomies and proportion of positive surgical margins. (Modified version of the National Comprehensive Cancer Network [NCCN] risk categorization is used in NPCR): *1* Low risk: T1–2, Gleason score 6 or lower and PSA <10 μg/l; *1a* very low risk: T1c, PSA < 10 μg/l, Gleason score 6 or lower, no more than four biopsies with cancer, total length of biopsies with cancer < 8 mm, a total of at least 8 biopsies taken, PSA density < 0.15 μg/l/ml; *1b* low risk (others): low risk that is not categorized as 1a; *1c* low risk (missing): missing information for categorization of low risk according to 1a/b; *2* intermediate risk: T1–2, Gleason score 7 and/or 10 < PSA < 20 μg/l; *3a* localized high risk: T1–2, Gleason score 8–10 and/or 20 < PSA < 50 μg/l; *3b* locally advanced: T3 and PSA < 50 μg/l; *4* regionally metastatic: T4 and/or N1 and/or 50 < PSA < 100 μg/l; no distant metastases (M0 or MX); *5* distant metastases: M1, bone scan shows signs of metastases, and/or PSA < 100 μg/l; *6* missing: missing information for categorization according to above

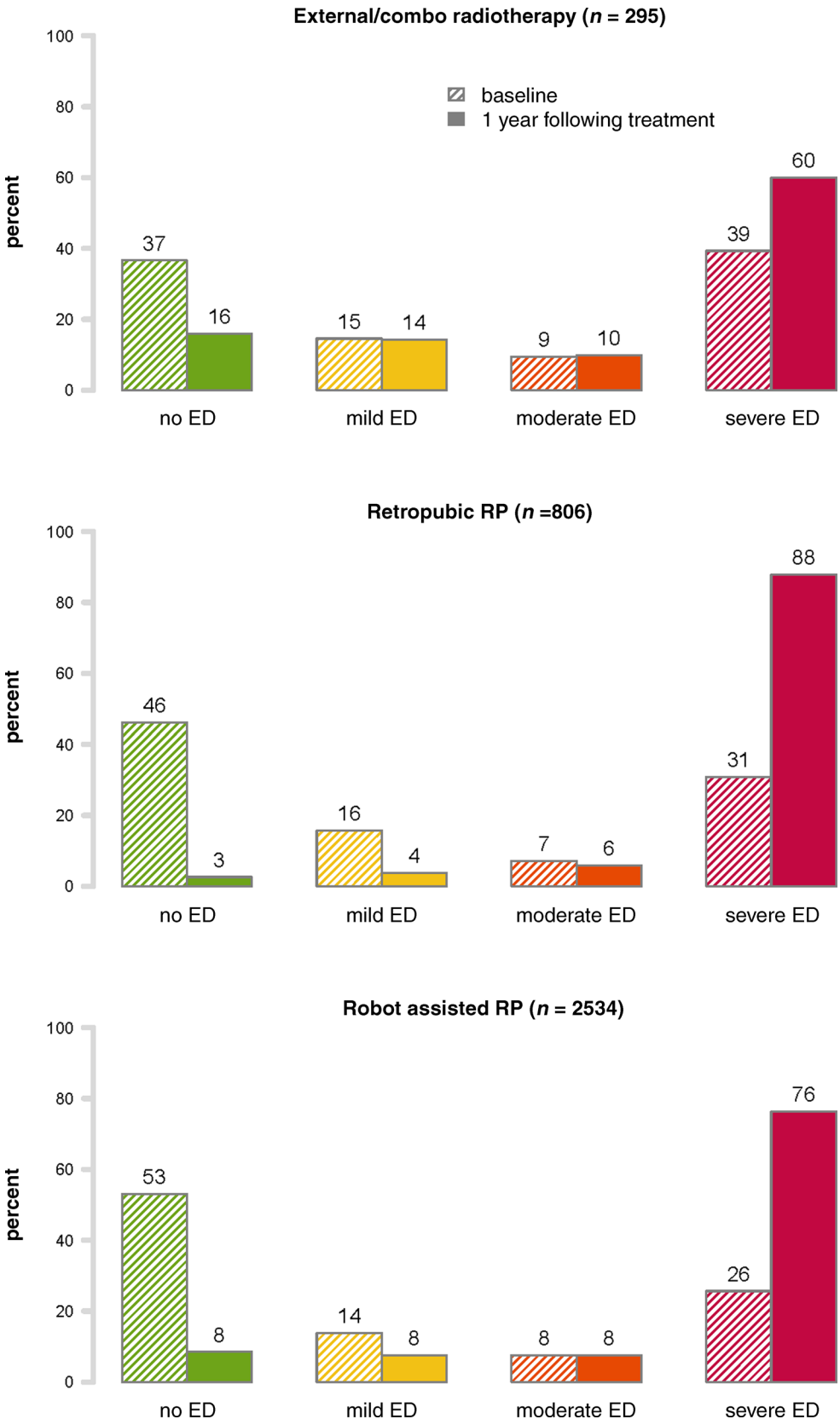

Fig. 2 Percentage of men with erectile dysfunction (*ED*) at baseline (before treatment) and 1 year after treatment. *No ED* No erectile dysfunction: International Index of Erectile Function-5 (IIEF-5) score > 20, *Mild ED* IIEF-5 score: 16–20, *Moderate ED* IIEF-5 score: 11–15, *Severe ED* IIEF-5 score: 0–10

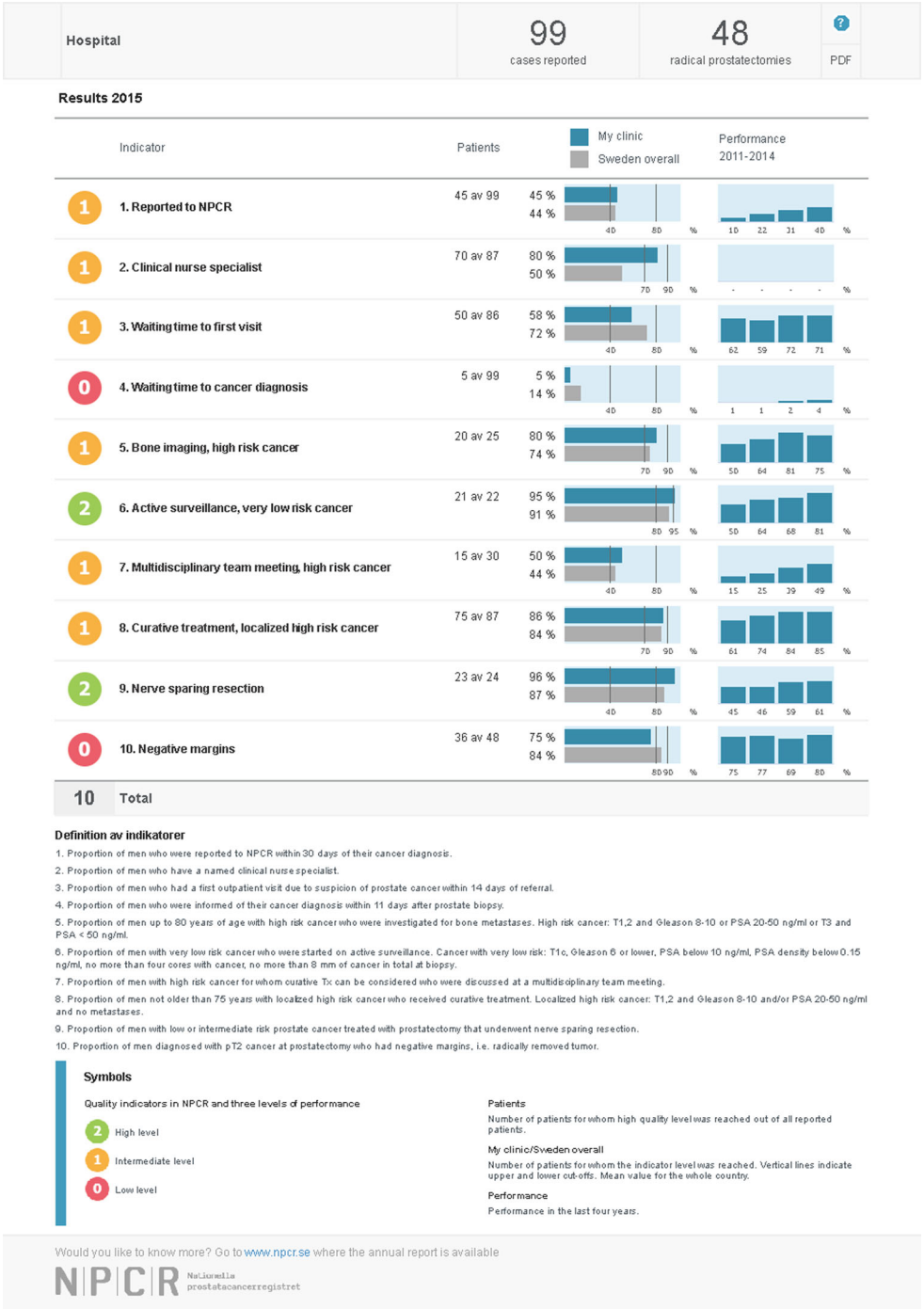

Fig. 3 "What's going on": Dashboard panel demonstrating result for a specific urology department for ten selected quality indicators

for patient-reported outcome measures (PROM) has been low, mostly due to logistical difficulties in the distribution of the baseline questionnaires. Data are available for 4645 men and show that the occurrence of adverse effects is considerable, in particular erectile dysfunction after surgery is common (Fig. 2). In 2015, PREM questionnaires were filled in by 1348 men and the response was largely positive with good ratings for information to the patient about the disease, extent of disease, treatment and treatment outcome, and anticipated adverse effects of treatment.

Recent developments: "What's going on," a dashboard panel

In 2014, NPCR launched "What's going on," a dashboard panel demonstrating the results for ten quality indicators at each department online within 24 h of registration (Fig. 3). The design of the dashboard panel has been described in detail elsewhere [8]. In brief, ten quality indicators were selected from the 2014 National Prostate Cancer Guidelines and include time to report to NPCR, waiting times, desig-

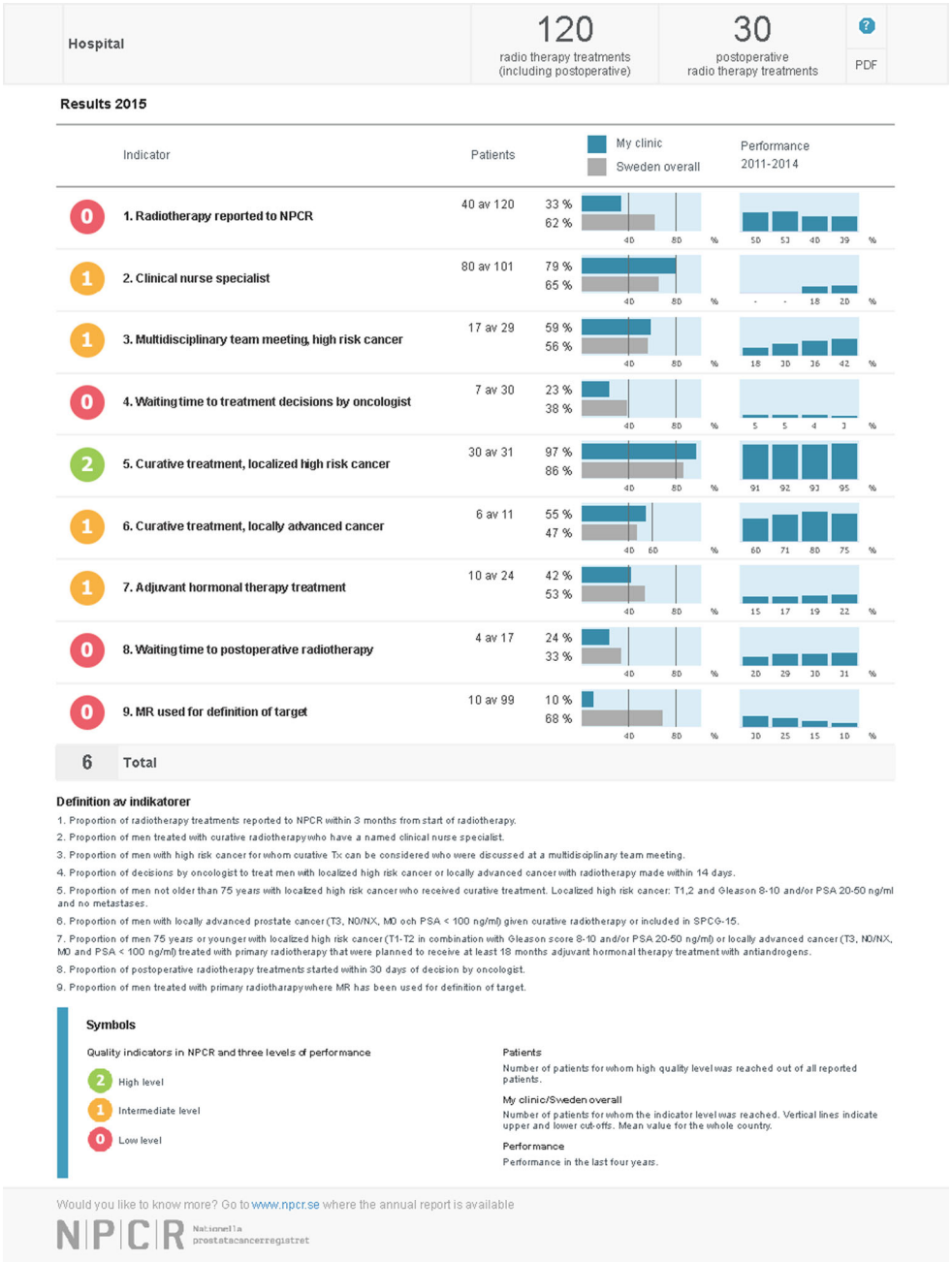

Fig. 4 "What's going on": Dashboard panel demonstrating result for a specific oncology (radiotherapy) department for nine selected quality indicators

nated clinical nurse specialist, multidisciplinary conference, adherence to guidelines for diagnostic work-up and treatment, and documentation and outcome of treatment. For each indicator, three performance levels were defined by the NPCR steering group together with the chairs of the guidelines and a care program.

The dashboard panel "What's going on" (*Koll på läget* in Swedish) is presented at the INCA platform and provides at-a-glance user-friendly feedback to care providers. It is not publicly available. In 2015, a similar dashboard panel and interactive set of reports was set up for radiotherapy (Fig. 4). In addition, there is a set of interactive of reports where health-care providers can select indicators for specific groups of patients and compare their results with the results at other departments in the region, or in all counties in Sweden, and comparisons can also be made between counties and regions (Fig. 5).

In order for these reports to fulfill their full potential for a major impact on clinical practice, their use has to be promoted by stakeholders including department and hospital leadership, clinicians, and patient representatives. In light of an international trend of systematic data collection for quality assurance, we believe that our experiences can be of value for similar initiatives outside of Sweden.

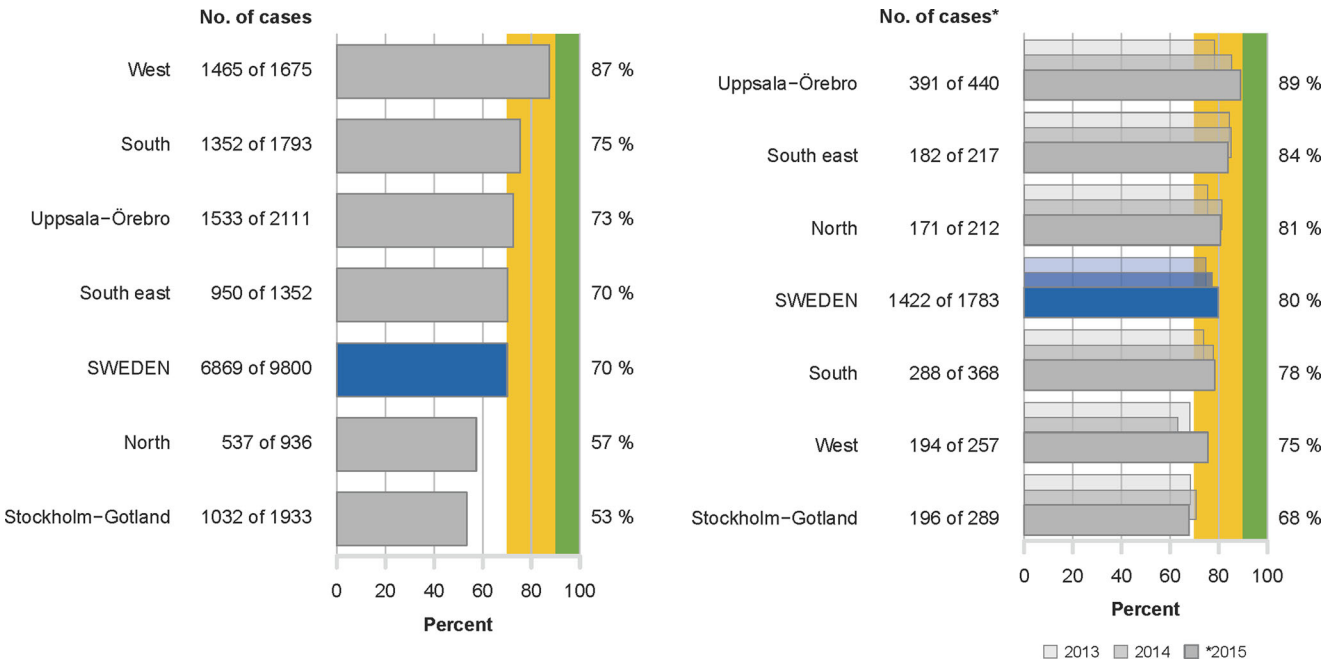

Fig. 5 **a** Proportion of men with prostate cancer in each health-care region in Sweden who had been assigned a navigator nurse during work-up and treatment in 2015. **b** Proportion of men with expected survival exceeding 5 years (age < 80 years) with localized high-risk or locally advanced prostate cancer examined with bone scan or other bone imaging by health-care region

PPC: graphical display of data for men with castration-resistant prostate cancer

The Patient-overview Prostate Cancer (PPC) is a new type of longitudinal quality registration that was recently launched by the NPCR. It is currently used for registration of men with hormonally treated prostate cancer, in particular castration-resistant prostate cancer (CRPC). There is a need for efficient data display for men with CRPC that is not met by current medical charts in Sweden. The disease history of these men is often complicated and sometimes long and it is time consuming to get an overview of this history in conventional electronic medical charts. Therefore, oncologists and urologists in the NPCR, together with the IT construction team at RCC Uppsala, have created PPC to meet the need for efficient data display. Furthermore, since PPC is a database on the INCA platform, any statistical software can be applied to these data.

Data are entered by staff and physicians into the PPC, which can subsequently provide:

- a) A dashboard panel displaying the patient's status in a user-friendly graph with an immediate gain for treating physician and patient in the clinic (Fig. 6).
- b) Metrics on care to department leadership including use and efficacy of drugs. For instance: How many patients are currently using drug A in our department? For how long did these men use drug A? How was quality of life affected by drug A?
- c) Metrics for benchmarking of prostate cancer care. A non-blinded report on performance at multiple departments is an ideal basis for peer comparison, which is an efficient way of improving care without the drawbacks of financial incentives.
- d) Comprehensive longitudinal data on treatment of men with advanced prostate cancer are collected, which will be a valuable resource for research.

The dissemination of PPC is led by a working group of oncologists, urologists, and nurses. To date, PPC has been introduced at 22 departments in Sweden and data on 2000 men have been registered. A helpdesk has been set up with access by phone and e-mail. The first national meeting for reporting staff was held in November 2016. Quarterly reports are distributed to each department with data on their use of drugs for CRPC (abiraterone, enzalutamide, radioligands, and chemotherapy) and with a 90-day latency a quarterly report is also distributed to pharmaceutical companies that subscribe to information from the PPC. The NPCR intends to develop the PPC so that it can also be used for men on active surveillance since there is also an unmet need of a structured follow-up of this large group of patients who are often monitored for a long time.

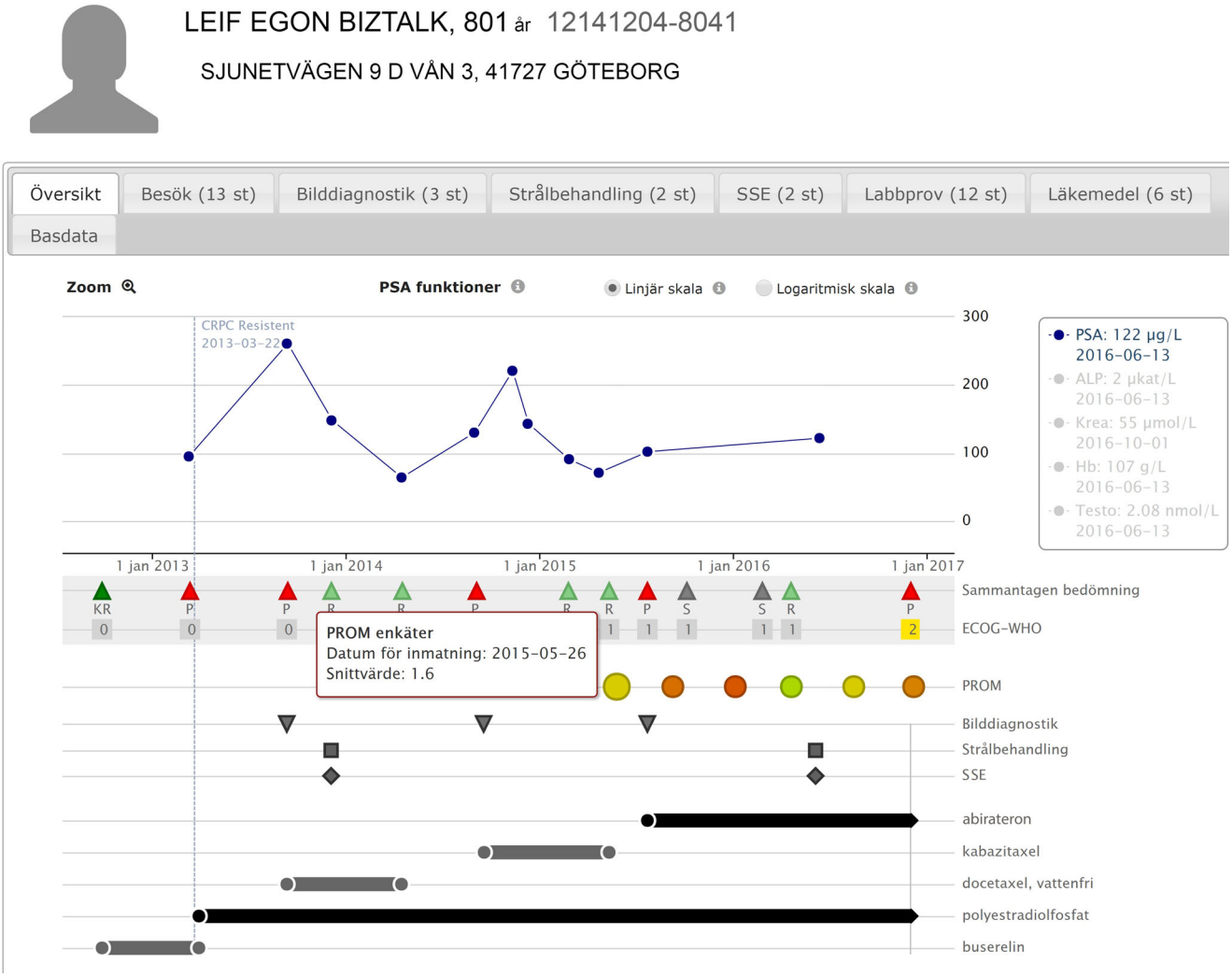

Fig. 6 Patient-overview Prostate Cancer (PPC) dashboard panel with timeline of disease history, therapy, and drug treatment. The dashboard panel shows a large set of patient data in a reader-friendly graph. This graph contains information from 90 pages in a medical chart. *Översikt* overview, *Besök* outpatient visit, *Bilddiagnostik* imaging, *Strålbehandling* radiotherapy, *SSE* symptomatic skeleton-related event, *Labbprov* results from blood tests, *Läkemedel* drugs, *KR* complete response, *R* response, *S* stable, *P* progression, *Datum för inmating* date for registration, *Sammantagen bedöming* global assessment

Some examples of improvements in clinical care

Although causality cannot be proven, we believe that there have been some effects on Swedish prostate cancer care as a result of registration and reporting in the NPCR.

Less use of unnecessary investigations

Since the early 2000s, the NPCR has regularly highlighted the proportion of men with low-risk prostate cancer who underwent a bone scan at each department in its annual report, in order to decrease the use of unnecessary investigations. There was a strong decrease in the proportion of men with low-risk prostate cancer who underwent bone scan, down from 45% in 1998 to 3% in 2008 and 2009 [9].

More use of treatment for locally advanced prostate cancer

Since SPCG-7 showed that there was a decrease in mortality in men with locally advanced prostate cancer who received androgen deprivation therapy (ADT) and radiotherapy compared with ADT only [10], there has been an increase in the use of ADT plus radiotherapy. For example, among healthy men aged 70–80 years with high-risk nonmetastatic prostate cancer, the use of curative treatment increased from 10% in 2001 to almost 50% in 2012 [11] and we believe the transparent reporting in NPCR for each department has contributed to this increase.

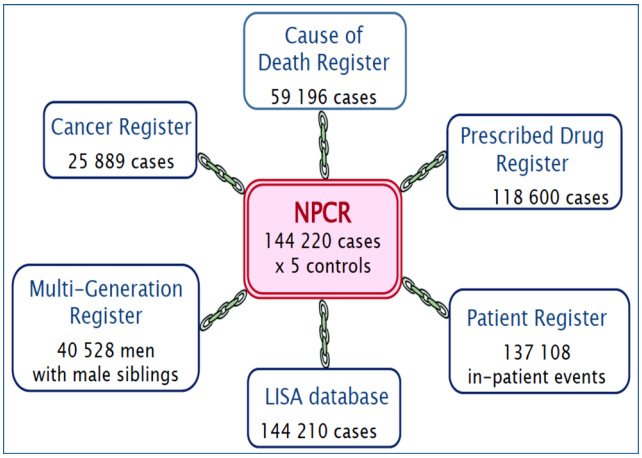

Fig. 7 Linkages and number of cross-linked men in the Prostate Cancer Database Sweden (PCBaSe) 3.0

Less use of treatment for low-risk prostate cancer

In 2007, the Swedish guidelines for prostate cancer care recommended active surveillance for patients with low-risk prostate cancer. There has been a subsequent strong increase in the use of active surveillance for men with low-risk prostate cancer from 40% in 2009 up to 74% in 2014 [12]. An even stronger decrease was observed for very low-risk prostate cancer (not N1or M1, stage T1c, Gleason Grade Group 1, PSA density less than 0.15/ng/ml/cm^3, four positive cores or fewer, and less than 8 mm of cancer in biopsies) [13] up from 57% in 2009 to 91% in 2014.

For some other quality indicators reported in "What's going on," no improvement has been observed. For example, waiting times for men with prostate cancer have remained long in every step of the diagnostic work-up and treatment.

Prostate Cancer Database Sweden: a basis for research

By use of the unique Swedish person identity number, the NPCR has been linked to a number of other national population-based health-care registers and demographic databases in Prostate Cancer Database Sweden (PCBaSe), a platform for clinical research ([14]; Fig. 7). In later versions of the PCBaSe, prostate cancer-free control men, randomly selected from groups of men matched to the index case on birth year and county of residence, were included to be used in case control studies. Since its inception in 2009, the PCBaSe has been the basis for 100 research papers on a wide range of topics including health-care patterns, outcome studies, and postauthorization safety studies (PASS) of rare adverse events of drug treatment (for a complete list of publications, see www.npcr.se/publikationer).

Conclusion

In conclusion, there is a need for a structured and rapid collection as well as a user-friendly display of data to be used as metrics for quality assurance and quality improvement in modern prostate cancer care. In Sweden, the NPCR tries to meet this need.

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